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ABSTRACT

The paper explores the impact of child variables, parent variables, and family resources (professional and informal supports) on the family's ability to cope with a child with special needs. Child variables include child gender, birth order, severity of handicap, degree of child dependency, extent of attachment, age of the child, and presence of behavior and social problems. Parent variables identified are education level, socio-economic status, parental attitudes toward their child's development and special needs, parental age and family size, number of parents in the home, and type and quality of personal and professional supports. Professional supports such as early intervention programs may decrease or increase parental stress. Informal support from family members or friends is related to low levels of parental stress. A model of family adaptation called the "T-Double ABCX Model of Family Adjustment and Adaptation" is discussed. The model identifies a pre-crisis adjustment phase, which is concerned with existing family types, strengths, and capabilities. The adaptation phase of the model concerns the family's ability to adapt to the crisis situation. The model looks at both the demands facing the family as well as the family's strengths and capabilities for meeting those demands. (Author/DB)

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Stress and Supports to Families with a Handicapped Child

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Abstract

Despite the proliferation of Early Intervention Services in both the United States and Canada, there is evidence to suggest that families with a handicapped member continue to experience significant levels of stress. This paper explores the impact of child variables, parent variables, and family resources (professional and informal supports) on the family's ability to cope with a child with special needs. A model of family adaptation proposed by McCubbin and McCubbin (1987) is discussed in terms of its applicability to families with a handicapped child.

Evidence has been accumulating that families with handicapped members are experiencing significant levels of stress in coping with their child's special needs (Crnic, Friedrich & Greenberg, 1983; Guralnick & Bricker, 1987). This has occurred despite the assistance received from early intervention services (Blacher, 1984; Crnic et al., 1983).

Typically, evaluations and analyses of early intervention services have assessed the impact of family support on the child's development, the child's interaction with his or her family, and changes in the environments experienced by the child (Casto & Mastropieri, 1986). However, these analyses have seldom examined the family's perceived stress and coping efforts as these relate to the child's handicaps. In addition, the child and family continue to be examined from univariate perspectives (for example, parent-child interactions, child communicative competence). The relevant variables have seldom been explored in combination from a multivariate perspective.

This paper will focus on the child, parent, and family resource variables that may affect stress in families with a handicapped child. A model of family adaptation proposed by McCubbin and McCubbin (1987) that incorporates these variables from a multivariate perspective is reviewed. It is proposed that this model may provide a framework for understanding stress and coping in families with a handicapped child.

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Stress in Families with Handicapped Children

There is evidence to support the view that families with a child who is handicapped experience more stress than families with typical children (Breslau, Staruch, & Mortimer, 1982; Holyroyd & McArthur, 1976; Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981). Burdens on the family, in addition to those associated with raising nonhandicapped children, may include: an inordinate amount of time spent on daily care needs of the child including ongoing medical care; increased financial responsibility for specialized equipment, transportation and so forth; difficulties in arranging respite and vacations; and ongoing, often intensive interactions with a variety of professionals. Blacher (1984) has stated that the child with special needs may have a negative effect on some or all of the following: the marital relationship, sibling relationships, relationships with friends and relatives, and planning daily activities or family vacations.

Despite the potential difficulties, some families appear to adapt surprisingly well without adverse effects on the well-being of the individual family members or overall family functioning (Beavers, Hampson, Hulgus, & Beavers, 1986; Friedrich & Shaffer, 1986). There is a growing interest in isolating variables related to stress in families with a handicapped member in order to help professionals understand why some families cope well and others do not. A brief review of a selected sample of these studies is discussed in terms of child variables, parent variables, and family resources.

Child Variables

Current research has identified a number of significant child variables that may affect family stress and coping. These include child gender (Bristol, 1979, as cited in Bristol & Schopler, 1983); birth order (Farber, 1960); severity of the child's handicapping condition (Bradshaw & Lawton, 1978); degree of child dependency and degree of responsiveness to parents (Holyroyd & MacArthur, 1976); extent of attachment and age of the child (Blacher, 1984); and presence of behavior and social problems (Chetwynd, 1985). In addition, the quantity and quality of parent-child interactions have been examined (Marfo & Kysela, in press).

These variables seem to be involved in the stress profiles which families exhibit, but in complex and ambiguous ways. For example, Holyroyd and McArthur (1976) found that parents of the more severely handicapped children experienced the greatest degree of stress. However, other investigators (Bradshaw & Lawton, 1978) found that the severity of the child's handicap was not as critical as personal parental characteristics.

There is a need to assess more thoroughly each dimension of the child's interaction with parents in order to obtain a complete analysis of influential variables affecting family stress and functioning. Factors such as severity of handicap, degree of responsiveness, and extent of attachment should be assessed individually and conjointly, and their mutual involvement in family stress should be examined in a multivariate model.

Parent Variables

In addition to the variables associated with children and their special needs, researchers have also examined a number of parent variables that could potentially affect family stress level. A significant set of factors affecting parental and family stress requires exploration. Parent variables include education level and socio-economic status (Segal, 1985); parental attitudes toward and perceptions of their child's development and special needs (Newberger, 1980; Sameroff & Feil, 1985); parental age and family size (Ragozin, Basham, Crnic, Greenberg, & Robsin, 1982); number of parents in the home (Beckman, 1983); and the type and quality of personal and professional supports the family experiences (Dunst, Trivette, & Cross, 1986; Schilling & Schinke, 1984).

There is much conflicting information regarding the importance of each of the parent variables identified above. Perhaps the most important factor is not any one of these variables, but how the parents perceive their particular situation (Bandura, 1977; Lazarus & Folkman, 1984). For example, Bradshaw and Lawton (1978) found that mothers' appraisal of their home situation was more important in determining level of stress than other variables such as child characteristics. There is a need to obtain a better understanding of the interaction of these personal variables with the family's ability to cope with the handicapped family member.

Family Resources

The existence of adequate family resources in terms of social support is a major factor in determining the capacity of parents to cope with their child with special needs (Dunst et al., 1986; German & Maisto, 1982). Family resources may be examined both in terms of formal, professional supports and informal support networks.

Professional supports. It has been suggested that although professional support is important to families with children who are handicapped, it does not always serve to decrease family stress level. In fact, in some situations, the professionals may actually increase the overall stress in the family (Becker, Bender, & Kawahe, 1976; Turnbull & Winton, 1983; Wiegerink, Hocott, Posante-Loro, & Bristol, 1980).

Early Intervention Programs are often a primary source of support to families with a handicapped child. Program variables that may affect family stress include extent of expected program involvement by the family, service delivery mechanism (e.g., home- versus center-based program), and program philosophy (e.g., structured versus unstructured didactic approaches, mainstreamed versus specialized learning environments) (Kysela, McDonald, Reddon, & Gobeil-Dwyer, in press). Preliminary research indicates that parents may experience stress when their expectations regarding an appropriate program for their child do not match the actual program that is provided by the professionals (Benson & Turnbull, 1986).

Two other variables that may affect stress are perceived competence of the professionals by the parents, and the values and attitudes of the professionals (Brown, 1971; Reisinger, Ora, & Frangia, 1970). Again, difficulties arise when there is a discrepancy between the parents' expectations or preferences and the actual situation encountered.

Informal supports. Informal support may be just as important or more important than professional support (Dunst et al., 1986; Granger, 1983). Informal supports may be provided by neighbors, friends, extended family, and church groups, to name just a few. The attitudes and values of others not directly involved in the family's program may have an effect on the family stress level. For the same reasons stated above, an individual may decrease or increase a family's level of stress depending on the match of attitudes and values with those of the parents. For example, support from family members, extended family, intimate friends, and/or friends seems to be related to low levels of stress exhibited by the family (Dunst et al., 1986; Granger, 1983). However, it is likely that the absence of support or discouraging attitudes toward the handicapped child by these significant others will adversely affect the family's coping and stress levels.

A final variable which has received little attention is the effect of the birth of a child with a handicap on siblings. Some studies have found increased behavioral and/or psychological problems in siblings (Seligman, 1975), whereas others have found little evidence of a negative impact (Gath, 1972). This is clearly an area where more research is required.

Need for a Family Systems Approach

Historically, researchers have dealt with a restricted set of independent and dependent variables when studying families with handicapped children and have not taken into account the interaction of the variables previously mentioned. It is no longer appropriate to focus exclusively on the stress reactions of one family member or to look at the effect of a single variable on the family's ability to cope. For example, there is evidence to suggest that mothers and fathers react differently

to the birth of a handicapped child (Schilling, Schinke, & Kirkham, 1985). Furthermore, families may react differently to the presence of a handicapped member depending on the particular stage that the family is in (Olson, McCubbin, Barnes, Larsen, Muxen, & Wilson, 1983).

A multivariate approach to the study of families and stress is required so that stress may be viewed in the context of the family system existing within a larger social system. Perhaps there are many conflicting research results because of the narrow focus of many of the studies.

McCubbin and McCubbin (1987) have provided a model of family adaptation that has the potential for enhancing our understanding of the way in which families function in the face of the chronic long-term stressors inherent in raising a handicapped child. The aim of the "T-Double ABCX Model of Family Adjustment and Adaptation" is to provide a model which will not only be able to predict the degree of disruption in functioning that a family is likely to experience in the face of a particular stressor event or change in the family system, but also the family's capacity to adapt and achieve a new balance in functioning after a major disruption or crisis occurs.

The first stage of the model is the pre-crisis Adjustment Phase and it is concerned with those family "types, strengths, and capabilities" which explain why some families are better able to adjust to relatively minor changes, transitions, or demands which do not require major alterations in family functioning. For example, a family may experience a minor shift in patterns of behavior as a result of changing from a two-car family to a one-car family.

The second stage of the model is called the Adaptation Phase. This phase is concerned with the family's ability to cope over time with a major event requiring family reorganization and adaptation. In other words, this phase focuses on the family's ability to recover from a crisis situation and achieve a new balance.

The Adaptation Phase of the model is the most important component in helping professionals understand the impact of the birth of a handicapped child on the family. The birth of a handicapped child may create a crisis situation that will never be resolved, thus requiring continuous adaptations on the part of family members. The family's ability to adapt to the crisis situation (the birth of the handicapped child) is a function of the family's regenerativity. Family regenerativity is in large part determined by a number of interacting variables including: the pile-up of demands on the family system (stressors, strains, and hardships experienced by the family at any point in time emerging from individual family members or from the community); family type or typology (predictable patterns of family life that are expected to influence family response to a crisis situation); family strengths and

resources (including tangible resources such as income, as well as intangible resources such as self-esteem); social supports available to the family including extended family, friends, and community resources; the family's appraisal of the crisis situation; and the family's problem solving and coping resources that have been used during previous crises. All of these variables interact and, in large part, determine how effectively the family will cope over time with the birth of a handicapped child.

This model may be a useful framework for conceptualizing the process by which families adapt to the chronic stressors inherent in raising a child with special needs. While many variables which have been associated with family members' increased vulnerability to stress (e.g., severity of handicapping condition, increased financial demands, lack of respite care) have been identified in the literature on handicapped children, there still lacks a coherent picture of how some families are able to manage surprisingly well in the face of overwhelming demands, while other family systems experience considerable disruption. This may be attributable to a failure on the part of researchers to take into account the dynamic interplay between the nature of the demands facing the family at any point in time, including those not directly associated with the special needs of the child, and the family's capability (appraisals, resources, coping strategies) to meet those demands. This model looks at both the demands facing the family as well as the family's strengths and capabilities for meeting these demands.

Summary

There is a good deal of conflicting literature in the area of stress and families with handicapped children. Part of the problem may be the need for more research applying a multivariate approach to the study of family stress. This approach takes into account the family as a system that is part of a larger social system. The model proposed by McCubbin and McCubbin (1987) allows researchers to take a more comprehensive view of the interactions of variables which may contribute to family stress and coping. If researchers and professionals have a better understanding of the variables affecting stress in a family, they may be in a better position to help families cope on a long-term basis with a child with special needs.

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Adjustment of Families with Handicapped Children[1]

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Abstract

This paper presents an overview of data from several phenomenological studies of families with mildly to severely handicapped children. The central themes of the parents' experiences are listed, and comparisons are made of common and unique themes across various types of handicapping conditions. Families of handicapped children often face unique problems adapting to the presence of a handicapped child. When attempting to work with these families, professionals are faced with a shortage of knowledge and understanding about the topic because families of handicapped children are a relatively recent subject of investigation (Gallagher, Beckman, & Cross, 1983). In a recent review of related literature, Gallagher et al. reported that families of children with handicaps experience severe stresses, including financial and marital. The nature of the handicapping condition, the educational level of the parents, the socioeconomic level of the family, the presence of one or two parents and siblings, and the nature of the child's educational program have all been implicated as possible sources of stress.

The series of studies summarized in this paper explored the nature and severity of children's handicapping conditions on family adjustment. The goal was to increase understanding of the parents' experience, with a focus on educational and daily living adjustments of the child and their impact on the family.

The handicapping conditions studied included (a) learning disabilities (six families of LD children, aged 10 to 15); (b) moderate mental handicaps (10 families of MMH adolescents); (c) hearing handicaps (5 families of HI adolescents); and (d) severe mental handicaps (10 families with MDH children from 6 years of age to adolescence).

Parent volunteers, contacted through community programs or parent support groups, were interviewed alone or in couples. The parents were asked to describe their experiences of parenting a handicapped child; the interviewer minimized further direction and probing. All interviews were tape- recorded, and parents were assured of confidentiality. Data were analyzed in terms of the predominant themes of

parent concerns. These themes are listed below. Analysis of interview protocols to determine the dominant themes used Colaizzi's (1978) six steps for phenomenological research. The form of theme presentation varied somewhat from study to study according to each researcher's style.

Central Themes: Families of Learning Disabled Children

1. Something is wrong with my child—but what? For example, there was a constant round of running to clinics, having tests done, living in agony waiting for results; "She (teacher) insisted he was just lazy and uncooperative."
2. I'm just the parent (no credibility status). For example, "I feel so invalidated by teachers and principals"; "I'm sorry they (teachers) can't credit parents with knowing anything."
3. The school, the teacher, or "the system". For example, "They aren't taking any action to help my child"; "She (the teacher) had 34 kids and she didn't have time enough, you know."
4. Support systems: teacher, mate, learning disabilities association. For example, "It was very frustrating to have these kiddies that weren't learning anything, and not knowing where to turn to get the support"; "and the staff there just went out of their way."
5. General and specific frustrations. For example, "I don't know what to do for this poor kid; the child is frustrated; he's going to get lost in the system; I hurt because I see my child hurt"; lack of teacher awareness of learning disabilities.
6. Self-esteem: child's self-esteem is low; self-esteem grows with small successes in the resource room. For example, "Oh yes, he spent such a long time feeling totally worthless, unworthy of anything."
7. Social stress/peer stress. For example, "Kids can be so cruel (teasing)."
8. Parent as teacher. For example, helps child at home; gets frustrated with child's disability when teaching at home; "I think most work that has come home ... either one or the other of us has been able to help him to some degree."
9. Parents as advocates. For example, "going to bat" for child's education; "It could have been ... a lot worse if he hadn't had parents that were willing ... to be advocates for him."
10. Perseverance is the key. For example, no quitting; "We never let him say, 'I can't do it.'"

Central Themes: Families of Moderately Handicapped Children

1. Recognition that "something was wrong," and confusion as to cause, with a need to explain "why."
2. Uncertainty about the nature of the child's difficulties, with lack of knowledge or understanding of any assessments.
3. Problems in seeking and finding appropriate placements and resources.
4. Parent determination, initiative, and involvement in the child's education.
5. Over the school years, there has been progress, but not enough; life, career education, language and academic skills have been inadequately developed.
6. Family and neighborhood relationships are basically good; the TMH child is well liked, but friendships are few; hobbies and recreational interests are few; interest in the opposite sex is limited.
7. Parental fears and concerns for the future of their TMH adolescent are many.

Central Themes: Families of Hearing Impaired Children

1. Personal development of mother: in decision-making capacity; in career (paid work and homemaker) and volunteer activities; in advocacy-parent groups; fighting for services. Roles: mother, teacher, advocate, supporter; with increased assertiveness, confidence, maturity, and self-esteem.
2. Strong emotions regarding the child: a strong emotional bond; a sense of pain and of the "burden" of the child; resurfacing emotions with fluctuations in intensity.
3. Parents have ultimate responsibility for the child and services.
4. Support and/or lack of support for mother from spouse, other children, relatives, friends, and professional people.
5. Independence/dependence of child: a continuing issue; successful independent living of the child is a goal.
6. Parent-professional relationships: the *individual* in the role makes the difference in the interactions of parents and professionals.
7. Programs: facilitating/nonchallenging; the ideal doesn't exist; parents have a limited role and decision making power;

mainstreaming has resulted in facilitating/nonfacilitating experiences.

8. Family relationships: spousal; hearing impaired child with other family members; parents and siblings; there have been both positive and negative effects of having a handicapped child.

9. Communications: methods used and their success; interest in sign language; communication is, for the most part, fluent.

Central Themes: Families of Multiple, Dependent Handicapped Children

1. Mothers generally feel that the presence of the child in the family has been the single most dominant and long-term influence in their life-pattern following the child's birth; care-giving demands are very high and often increase with the child's age.

2. The participating parents had strong feelings (negative or positive) about the quality of assistance given to their handicapped child or themselves by the various professionals or social agencies they have come in contact with.

3. The parents expressed a great deal of concern and apprehension about the long-term future of their severely and multiply handicapped child; what will happen to their child when they (the parents) can no longer act as primary caregivers?

4. Parents experienced ongoing stress and anxiety that appeared to relate to circumstances, for example, care-giving demands and problems with professionals.

5. The presence of a severely and multiply handicapped child in the family had a very significant effect on the other family members; many parents felt that other siblings had frequently missed out on parental attention because of the needs of the handicapped child.

Conclusion

Many limitations of the studies reported prevent one from drawing definitive conclusions from the findings. The samples were small. As well, the various projects were conducted and analyzed by different interviewers and researchers. Themes were identified and organized in different ways. In addition, because the data were from unstructured parent interviews, parents may have been selective in the aspects they reported and emphasized. For example, they may have focused on most recent or most stressful events. Nevertheless, some trends are evident and worthy of consideration and further study.

It is apparent that these families, over the entire range of handicapping conditions, experienced some confusion regarding the nature and

extent of the handicapping condition. However, the more severe the condition, the less ambiguous the diagnosis, although this does not necessarily hold for the treatment or course of action. Indeed, for all handicapping conditions there are some feelings of parental helplessness and feelings that the schools, social service agencies and, in general, support systems are not sufficiently facilitating and could be doing more. The presence of a handicapped child requires parents to assume a strong role as advocates. A handicapped child has a strong impact on family relationships, both positive and negative. For moderate to severe mental handicaps, greater fears for future adjustment and care were expressed, whereas for families with hearing impaired children communication was a central concern. Diagnosis was a major concern of families with learning disabled children.

Thus for professionals working with families having a handicapped child, there are general and specific concerns warranting sensitivity and support. While all of the themes may not be relevant to specific families, professional awareness may serve to alleviate some of the parent-professional ambiguities and potential areas of conflict by allowing development of a mutually supportive parent-professional partnership.

Note

1. An earlier version of the paper was presented as three posters at the Severe and Multiple Handicaps: Alternative Futures Conference, Edmonton, Alberta, May 1987. The data describing the families with moderately handicapped children have been added from an earlier paper (Wilgosh, 1985). The project was partially funded by a grant to the first author from the Alberta Advisory Committee for Educational Studies.

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